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Citation: McKenzie, Karen, Metcalfe, Dale, Michie, Amanda and Murray, George (2020) Service provision in Scotland for people with an intellectual disability who have, or are at risk of developing, dementia. *Dementia*, 19 (3). pp. 736-749. ISSN 1471-3012

Published by: SAGE

URL: <https://doi.org/10.1177/1471301218785795>
<<https://doi.org/10.1177/1471301218785795>>

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Service provision in Scotland for people with an intellectual disability who have, or are at risk of developing, dementia

Karen McKenzie, Dale Metcalfe, Amanda Michie, George Murray

Abstract

This research aimed to identify current national provision by health services in Scotland in relation to proactive screening and reactive assessment for people with an intellectual disability in Scotland who have, or are at risk of developing, dementia. Staff from 12 intellectual disability services, representing the 11 health board areas in Scotland, completed an online questionnaire which asked about proactive screening and reactive assessment for people with intellectual disability who had, or were at risk of developing, dementia as well as suggested areas for improvement. All of the areas provided services for people with intellectual disability who have, or are at risk of developing, dementia, but differed as to whether this was reactive, proactive or both. Nine services offered intervention following diagnosis. The most common elements used across both proactive screening and reactive assessment were conducting a health check, using a general dementia questionnaire designed for people with an intellectual disability and direct assessment with the person. Clinical psychology and community learning disability nurses were the professions most likely to be involved routinely in both proactive screening and reactive assessments. The psychometric properties of the most commonly used assessments of cognitive and behavioural functioning were mixed. The areas of improvement suggested by practitioners mainly related to ways of improving existing pathways. This research represents the first step in providing an overview of service provision in Scotland. There was some inconsistency in relation to the general and specific components which were

involved in proactive screening and reactive assessment. Implications for service provision are discussed.

Keywords: Intellectual disability; dementia; service provision; screening; assessment

Introduction

It has long been recognised that people with Down syndrome face an increased risk of developing early onset Alzheimer's disease compared with their typically developing peers (Strydom et al., 2010). This recognition has resulted in the introduction of proactive screening as part of service provision in a number of areas, in addition to assessment in response to concerns about decline in the person's functioning (McKenzie, Murray, McKenzie, & Muir, 1998; McKenzie et al., 2000; Rowe, 2014). Proactive screening occurs when individuals who are at increased risk of dementia are screened on a regular basis prior to showing any signs of deterioration. Reactive assessment occurs when the person is assessed in response to concerns about a deterioration in their functioning.

Recent guidelines acknowledge the importance of proactive screening for dementia for many people with Down syndrome and the role of reactive assessment for all individuals with an intellectual disability in response to concerns being raised in relation to a deterioration in functioning (BPS DCP & RCP, 2015). It is recommended that services obtain a baseline assessment by age 30 for every adult with Down syndrome against which to compare any future changes in cognitive and/or adaptive functioning (Turk, Dodd, & Christmas, 2001). If a person is suspected of having dementia, then he/she should be monitored and reassessed regularly (BPS DCP & RCP, 2015).

Along with the general population, the life expectancy of people with an intellectual disability has increased, meaning that individuals with an intellectual disability that is not a result of Down syndrome are also at an increased risk of developing dementia (McCarron, McCallion, Fahey-McCarthy, Connaire, & Dunn-Lane, 2010). The life expectancy of people with Down syndrome in the UK is approximately 60 years (Torr, Strydom, Patti, & Jokinen, 2010) and the average age of those in Scotland reported in 2008 was 40 (Mantry et al., 2008). Neuropathological signs of Alzheimer's disease are present in almost all people with Down syndrome aged over 40 and clinical signs are common in those aged over 50 (see Head, Silverman, Patterson, & Lott, 2012), although not all will develop dementia. Prevalence rates vary according to the age ranges of the participants and

whether they have Down syndrome or another cause of intellectual disability. A review by Strydom et al. (2010) suggests prevalence for those with an intellectual disability aged 60 and over is approximately 6.1%, while it is between 30-40% for those who have Down syndrome aged 50 and 59, again indicating that the development of dementia is not inevitable for all people with Down syndrome. More recent research has found prevalence rates for people with Down syndrome to be consistent with these figures (McCarron, McCallion, Reilly & Mulryan, 2014).

As well as the impact on the person, the growing number of people with an intellectual disability and dementia presents a range of financial and other challenges for service planners and providers as well as staff and carers who are providing day to day support. In respect of the financial challenges, it is recognised that there are significant economic costs associated with caring for those with dementia. While the specific costs of supporting people with an intellectual disability and dementia are hard to determine, Alzheimer's Disease International (2010) estimated that the overall worldwide costs of dementia would increase by 85% to US \$1,117 billion by 2030.

Research also suggests that service providers may feel unprepared to provide support to people with an intellectual disability who have dementia because their needs may differ from those of the general population in many respects (McCarron et al., 2010). These challenges may include staff feeling that they lack the knowledge, skills and experiences to support this group of people. In addition, the funding systems and infrastructure regarding existing service provision may be inadequate or unsuitable (McCarron et al., 2010; McKenzie, Baxter, Paxton, & Murray, 2002). For example, people with an intellectual disability and dementia may have a differing course and progression of the disease, meaning that the types of support required as the disease progresses may differ from those required by people with dementia who do not have an intellectual disability.

Early signs of dementia in people with an intellectual disability are more likely to present as changes in behaviour and personality, whereas cognitive changes, particularly in memory, are more common indicators of dementia in typically developing individuals (see Torr et al., 2010). In the later stages of

the disease, the individual with an intellectual disability may experience a range of co-morbid health conditions including respiratory difficulties, recurrent infections, constipation and complications associated with immobility (e.g. McCarron, Gill, McCallion, & Begley, 2005), all of which will require more specialist care. The rate of deterioration of people with an intellectual disability can also be faster than in those without an intellectual disability, with early studies indicating an average period of six years between diagnosis and death (Prasher & Krishnan, 1993) and more recent studies indicating a duration 6 to 6.25 years and a median survival period of 7 years (McCarron et al., 2014). This can mean that services face the challenges of needing to both plan proactively for change and respond quickly when it occurs.

These challenges are increased because the information on which to base service planning is often patchy, for example, prevalence rates varying according to the type and size of the population studied. In addition, very little is known about the prevalence, course and progression of dementia in people with an intellectual disability who do not have Down syndrome, although research has indicated that it is two to three times more prevalent compared with the general population (Strydom, Hassiotis, King, & Livingston, 2009).

There are several reasons why it has been difficult to obtain accurate information about people with an intellectual disability and dementia on which to base service provision and planning. Assessing changes in cognitive and adaptive functioning relies on information being available about the person's functioning prior to the onset of dementia. This requires the availability of appropriate assessments, suitable for individuals with an intellectual disability which have good psychometric properties and reliance on informants to provide accurate information about the person's functioning over time, particularly for individuals with severe or profound impairments who are unable to complete direct assessments or self-report measures (See McKenzie, Metcalfe, & Murray, 2018). Furthermore, people with an intellectual disability form a heterogeneous group who vary widely in their cognitive and adaptive functioning. Little is known about how these differences might

impact both on the patterns of normal aging or course and progression of dementia, making it difficult to disassociate changes due to normal aging from those that may indicate the onset of dementia (Strydom et al., 2009; McKenzie et al., 2002).

Proactive screening for dementia is also complex because it can be difficult to distinguish behavioural and cognitive changes that mimic those associated with dementia but are due to other factors, from those that are due to dementia. Such factors may include depression, sensory problems or hypothyroidism, or are due to environmental or other issues, such as the effect of medication, bereavement, changes in routine or abuse (BPS DCP & RCP, 2015; McKenzie et al., 2002; Paxton, McKenzie, & Dickson, 2001). As such, it is important that an assessment includes multiple components. Recommended minimum components (BPS DCP & RCP, 2015; Turk et al., 2001) include:

- a check of the person's physical health
- a review of past, recent and current life events
- exploration of any negative changes in the person's adaptive functioning, behaviour, memory, orientation, mental state and mood, using both interview and objective assessments where appropriate
- assessment of cognitive and adaptive skills

In the context outlined above, this research aimed to identify current national provision by health services in Scotland in relation to proactive screening and reactive assessment for people with an intellectual disability who have, or are at risk of developing, dementia. This was to help inform the strategic planning, development and delivery of good quality services for individuals with an intellectual disability and dementia, their families and carers.

Method

Design and ethical approval

Ethical approval for the project, which was conducted in 2017, was provided by the first author's educational establishment. The research had an observational design and information was gathered via an online survey of practitioners working across Scotland regarding proactive screening and reactive assessment for people with an intellectual disability who had, or were at risk of developing, dementia. We also gathered information on practitioner views about service provision and asked for suggested areas for improvement. We use the term 'intellectual disability' throughout except where referring to services or professionals, such as community learning disability nurses.

Recruitment

As clinical psychologists in Scotland are usually the profession involved in assessing cognitive and adaptive functioning of individuals with an intellectual disability who have, or are at risk of developing dementia, recruitment to the study was carried out via the heads of clinical psychology intellectual disability services in Scotland. These heads, who led services which covered all of the NHS Health Board areas in Scotland, were contacted via email. They were provided with information about the study and asked to forward the information and link to the online survey to the most appropriate clinical psychology staff member(s) who provided services to people with an intellectual disability and dementia. These staff members in turn were asked to complete the online survey in respect of their service, in conjunction with other team members where appropriate. Staff from all of the health board areas covered by the service heads who were contacted responded.

Participants

Responses were received from staff from 12 intellectual disability services. As per the recruitment process, while 12 individual responses were received, this represented a service in Scotland providing proactive screening and reactive assessment for people with an intellectual disability with or at risk of developing dementia. There are 14 health board areas in Scotland, but some of the smaller areas receive some more specialist services from other health board areas. The 12 responses

represented 11 main health board areas in Scotland that provided the services of interest to the study. Information was primarily provided by clinical psychologists, often in conjunction with other team members, who were working in the same services.

Results and discussion

Twelve services in Scotland who provided the services of interest to the study participated. The 12 responses represented 11 main health board areas in Scotland, giving a national picture of service provision. The results are presented as descriptive data rather than being analysed statistically. As the total number of services who participated was 12, only numbers, and not percentages, are provided in the tables below.

Overview of service provision

Proactive screening and reactive assessment

All of the participating areas provided services for people with an intellectual disability who have, or are at risk of developing, dementia. Seven services provided both proactive screening and reactive assessment to people with Down syndrome, with the remaining areas providing reactive assessment only. Eleven services provided a reactive assessment to individuals without Down syndrome, while one area provided both reactive and proactive input. Seven services had been providing reactive input for at least ten years, one for eight years, while the remaining services were unsure. Proactive screening pathways had been in place for a shorter period, with six services noting they began from 2004 onwards. The remaining services were unsure of when the service had first begun. The typical age at which proactive screening began ranged from 18 to 40 years (mean = 32.6, SD = 8.1). Nine services offered intervention once a diagnosis of dementia was given to the individual. The mean estimated number of proactive screens that had taken place in the past year was 30 (SD = 23.4), with a range of 0-72 across the 12 services. The equivalent figures for reactive assessments were 21.6 (SD = 20.1) with a range of 1-64.

The proactive screening and reactive assessment processes

General components of assessment

Table 1 shows the number of services including each element in proactive screening, reactive assessment or both. The most common elements used across both proactive screening and reactive assessment were conducting a health check, using a general dementia questionnaire and direct assessment with the person. The most common elements in reactive assessment were assessment of daily living skills and gaining information from informants. Once initial assessment had occurred, individuals were typically reassessed between six months (four services) and 12 months (six services) later. The remaining two services noted that the assessment period varied according to the perceived needs of the person. Table 2 illustrates the frequency with which different professionals were typically involved in proactive screening and reactive assessment.

Table 1. *The number of services including each element in proactive screening, reactive assessment or both*

Element	Proactive only	Reactive only	Both
Health check	0	4	7
Neuropsychological assessment	1	6	2
Assessment of living skills	1	7	2
General dementia screening, i.e. an assessment using a dementia specific screening tool	1	5	6
Informant interviews/questionnaires	1	6	5
Direct assessment of the person	1	5	6
Psychological assessment	1	5	5

Assessment of social and environmental factors, e.g. staffing levels and staff characteristics	1	5	4
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Table 2. *The frequency with which key team members were typically involved in proactive screening, reactive assessment or both*

Profession	Proactive only	Reactive only	Both
Clinical Psychologist	0	5	6
Community Learning Disability Nurse	2	6	4
Psychiatry	0	9	2
Speech and Language Therapist	0	2	0
Occupational Therapist	1	4	1
GP	0	2	0

Specific components of assessment

The services reported on the inclusion of specific components of assessment in their proactive screening, reactive assessment processes or both. These included health screening, assessment of cognitive and adaptive functioning and dementia specific assessments.

Health screening

Table 3 shows that the most common elements in the health screen reported by the participating services.

Table 3. *The number of services including different elements in their health check in relation to proactive screening, reactive assessment or both*

	Proactive only	Reactive only	Both
Assessment of the person's history	1	6	5
Thyroid test	1	5	4
Cardiovascular assessment	0	4	2
Depression assessment	0	4	1
Hearing assessment	1	3	4
Vision assessment	1	3	4

Cognitive assessment

A total of 11 different cognitive assessments were used by the participating services. The most commonly used were the Dementia Questionnaire for People with Learning Disabilities (DLD; Evenhuis, 1992; Evenhuis, Kengen, & Eurlings, 2009), the Cambridge Cognitive Examination modified for use in a group with Down syndrome (CAMCOG-DS; Hon, Huppert, Holland, & Watson, 1999) and the Severe Impairment Battery (SIB; Saxton, McGonicle, Swihart, & Boller, 1993).

The DLD was used by all 11 services (one for proactive assessment, four for reactive assessment and six for both purposes). The CAMCOG-DS was used by nine of the participating services (one for proactive assessment, three for reactive assessment and five for both purposes). The SIB was used by eight of the participating services (one for proactive screening, five for reactive assessment and two for both purposes).

Assessments of daily living skills

The participating services reported using six different assessments of adaptive functioning. The most commonly used measures of daily living skills were the Adaptive Behaviour Assessment System (ABAS; Harrison & Oakland, 2015) and the Vineland Adaptive Behaviour Scales (VABS; Sparrow,

Cicchetti, & Saulnier, 2016). The ABAS was used by eight services (five as a reactive assessment and three for both proactive and reactive assessment). The VABS was used by six services (three for reactive assessment and three for both reactive and proactive assessment purposes).

Service improvements and developments

Adequacy of current service provision

Six of the services felt that the proactive screening, reactive assessment and diagnostic processes for dementia in people with an intellectual disability were probably adequate in their area. Two services felt they were definitely adequate, while one service felt they were probably not adequate and one felt uncertain. The remaining services did not respond. All the respondents considered their own knowledge and that of their team members in this area to be good or very good. The majority (7/10 of those who responded) felt the knowledge of front line support staff was good, with the remainder being neutral on this point. The knowledge of external NHS staff who were not intellectual disability specialists was considered to be good by four respondents, poor by one and the others were neutral about this.

Suggested areas for improvement

A number of suggestions were provided for ways in which service provision could be improved across Scotland (see Table 4). The most common areas, both of which were referred to by six services, related to improving knowledge, e.g. through training and awareness raising, and ways to improve existing pathways, for example by developing a central database which would identify when assessments were due and had been completed. In addition, three services highlighted the need to take account of guidelines, policies and government targets, such as HEAT targets. The latter are set by NHS Scotland and Health Directorates and comprise of targets related to Health improvement, Efficiency, Access to treatment and Treatment.

Table 4. *Suggested areas for service improvement*

Suggested areas for improvement	Examples
Processes and systems	<ul style="list-style-type: none"> • Clearer pathways • Central database • Method of alerting when assessments are due/when people reach age that baseline assessment is due • Agreement on eligibility criteria • Timeline for assessments to be completed
Resources	<ul style="list-style-type: none"> • Additional resources to manage administration associated with screening pathway
Adherence to guidance, targets and evidence base	<ul style="list-style-type: none"> • Ensure practice and interventions are in line with guidelines/HEAT targets • Use evidence-based tools/assessments • Need for consistency and equity across areas
Post-diagnostic care	<ul style="list-style-type: none"> • Development of post-diagnostic pathway • Provision of staff training around post-diagnostic care
Enhancing the ability to identify dementia in people with an intellectual disability	<ul style="list-style-type: none"> • Ongoing provision of training/awareness raising sessions to wide range of groups, including topics such as early indicators of dementia, diagnostic overshadowing, risk factors and strategies to help • Organising a conference targeted at family members

Discussion

All of the participating services provided a service to people with an intellectual disability who had or were at risk of developing dementia, whether proactive, reactive or both. The ultimate aim of both proactive screening and reactive assessment is to facilitate the early diagnosis of dementia, in order to plan and provide flexible and appropriate support for individuals, their family and carers, as their needs change over time with the progression of the disease (BPS DCP & RCP, 2015). The results

suggest that all of the participating services in Scotland are helping to support early diagnosis through the provision of reactive and/or proactive assessment.

Reactive assessment and proactive screening are generally multi-disciplinary, with clinical psychology, nursing and psychiatry being the professions that are most frequently involved on a routine basis. Speech and language therapists, occupational therapists and GPs tended to be involved when assessments were a result of concerns. Addressing the multiple components of a comprehensive proactive screen and reactive assessment requires multi-disciplinary input (BPS DCP & RCP, 2015) with different members talking on particular aspects of the proactive screening and reactive assessment process. The study found that clinical psychology was the profession most likely to be involved routinely in both proactive screening and reactive assessments, followed by community learning disability nurses. The significant involvement of both of these professions is unsurprising given the importance of assessing cognitive and behavioural changes and physical health status. A number of neuropsychological/cognitive assessments require the user to be an appropriately qualified psychologist, meaning the clinical psychologist is the most likely team member to conduct these.

As a number of physical health conditions may result in changes that are also common indicators of dementia, it is important to inform differential diagnosis by conducting a health check. These may include depression, sensory problems or hypothyroidism, or result from the use of medication (BPS DCP & RCP, 2015; McKenzie et al., 2002; Paxton et al., 2001). Community learning disability nurses have traditionally conducted health screenings and will often be the professional who provides ongoing support to the individual during their journey through the proactive screening, reactive assessment and intervention pathway (Paxton et al., 2001; Rowe, 2014). The most common elements in the health screen in the present study were obtaining the person's medical history and thyroid check. In addition, a number of services would refer to the person's GP for a full health

check. Some areas also had bespoke services that included specialist assessment, e.g. in relation to vision. Rowe (2014) highlights the importance of intellectual disability service professionals working in partnership with both GPs and other services, as required, to ensure a comprehensive assessment and treatment approach for the individual. This is reflected in parts of the UK by the introduction of payments to GPs who provide dementia screening to people with an intellectual disability (NHS England & NHS Employers, 2013), although this does not apply in Scotland, where the current study took place.

The study highlighted that a number of different assessments of both cognitive and adaptive functioning were used across the different services. In respect of cognitive assessments, 11 different ones were used, the most common being the DLD, the CAMCOG-DS and the SIB. Research has suggested that the DLD may be less suitable for use with people with a severe intellectual disability (Boada et al., 2018). The sensitivity and specificity of the DLD were good when used with people with Down syndrome and dementia, but more variable for people with an intellectual disability and dementia who did not have Down syndrome. It was also found to have poor inter-rater reliability on some items, particularly those relating to behaviour and disturbance, although reliability was better for individuals who were less able (McKenzie et al., 2018). The reliability of the CAMCOG-DS is unknown, but it has been found to have validity as a way of measuring changes over time which are related to Alzheimer's disease (Ball et al., 2006). As with the DLD, it is not recommended for use with people with a severe intellectual disability and it is suggested to be less useful for those with more advanced dementia (see McKenzie et al., 2018, for an overview). Research suggests that the SIB is used relatively frequently with people with an intellectual disability although it was not specifically designed for this group of people. There is relatively little evaluation of the psychometric properties of the measure as used with people with an intellectual disability, but the existing research indicates that it shows good test-retest reliability and concurrent validity (McKenzie et al., 2018).

There are a number of challenges involved in conducting cognitive assessments directly with individuals with an intellectual disability. These include the fact that assessments commonly used with typically developing individuals may be unsuitable for, or not standardised with, people with an intellectual disability (Zeilinger, Stiehl, & Weber, 2013). Those assessments that are specifically designed for use with people with an intellectual disability may still have a floor effect when used with people with a severe intellectual impairment, with many or all items being too difficult (see McKenzie et al., 2018). Services, therefore, may need to use different assessments depending on the ability level of the individual. Services may also be constrained by the assessments that were used at baseline assessment. This can be problematic if the original assessments are obsolete at the time of follow up or are shown to have poorer psychometric properties than alternatives. However, if older versions of assessments which have been used at baseline are replaced by newer versions which have different norms, or by a different assessment, any changes in the person's functioning may be for this reason rather than being due to dementia.

There was less variation in the measures of adaptive functioning used by the different services, with most services using a version of the ABAS or VABS. As with the cognitive assessments, issues arise when assessments are updated but the older version was used at baseline. For example, while the VABS II has been used to track behavioural decline in people with an intellectual disability and dementia (e.g. McKenzie et al., 2000), there is currently no research available about the use of the most recent version with this group (McKenzie et al., 2018). Similarly, limited information is available about the psychometric properties of the most recent version of the ABAS in relation to people with an intellectual disability. Therefore, the performance of this version when used as part of a dementia assessment with this group is unknown (McKenzie et al., 2018).

This highlights a need for ongoing research into the assessments that are used for proactive screening and reactive assessment for dementia with people with an intellectual disability. In

addition, staff need to regularly update their knowledge to ensure that they use the most appropriate assessments in light of new research and the development of new measures.

The perceived adequacy of service provision varied across respondents, although levels of team knowledge were considered to be good. An important aspect of good service provision is the level of knowledge of specialist intellectual disability staff (BPS DCP & RCP, 2015), while the knowledge of family and/or paid carers is also important in terms of identifying and supporting people with an intellectual disability and dementia (McKenzie et al., 2002). While most respondents considered the knowledge of front line staff to be good, the need to continue to improve knowledge, by providing training and awareness raising sessions to family and paid carers was identified by six participants. Other areas for service improvement largely related to processes and systems and the resources to support the administration of these. There was also a recognition of the need to adhere to good practice guidelines and to provide an evidence-based service. The results overall suggest the need for a more consistent approach to service provision across Scotland while allowing flexibility to meet the needs of local areas.

Limitations of the study

The findings of the study need to be considered in the context of its limitations. While the responses represented the views of practitioners working in services across Scotland, only one response was provided from each service, rather than from each staff member within the service. While these responses, often represented input from more than one professional in the service, it is possible that team members who did not contribute may have differed in their views or knowledge about service provision. In addition, the study had a specific focus on services for people with an intellectual disability and dementia, and it may be that some services provided components that would be included in a dementia screen or assessment as part of routine care to all people with an intellectual disability, such as a health screen. As such, these components may not have been reported within the responses from practitioners.

Conclusion

The results indicate that all services across Scotland provide reactive assessment and/or proactive screening to individuals with an intellectual disability who have, or are at risk of, developing dementia. There were some differences in the services across Scotland in relation to the general and specific components which were involved in proactive screening, reactive assessment or both. Both proactive screening and reactive assessment have benefits and drawbacks. Proactive screening has the benefits of providing a baseline of the person's functioning, against which functioning in future years can be compared. Regular screening also enables changes in the person's status to be picked up quickly. It does, however, require considerable clinical and administrative resources and may be stressful for the person with an intellectual disability. Reactive assessment has the benefit over proactive screening of avoiding potentially unnecessary and stressful regular assessment for the individual. A drawback is that its reliability and usefulness is likely to be reduced if there is no existing baseline information against which to compare the person's current functioning, thereby delaying the diagnostic process (BPS DCP & RCP, 2015).

The results overall suggest the need for a more consistent approach to service provision across Scotland while allowing flexibility to meet the needs of local areas. These needs may be influenced by available resources, the preferences of individuals with an intellectual disability about service provision and individual characteristics, such as level of intellectual disability, which influence which assessments are appropriate to use. The guidelines developed by the BPS DCP and RCP (2015) offer a helpful framework for services who wish to ensure that their practices are comprehensive and evidence based. Adoption of the guidance may also facilitate a greater consistency in service provision across Scotland.

This research represents the first step in providing an overview of service provision in Scotland. Further, more detailed information is now needed about the effectiveness, efficiency, validity, reliability and social acceptability of proactive screening, reactive assessment and intervention

processes in order to inform the strategic planning, development and delivery of good quality services for individuals with an intellectual disability and dementia, their families and carers in Scotland. This is particularly important given that little is known about the views of people with an intellectual disability about the perceived benefits and drawbacks of proactive screening for dementia and that families and carers may have mixed views about knowing that the person they care for is developing dementia (see Rowe, 2014). Indeed, while it is noted that proactive screening of individuals can be extremely helpful in providing baseline information against which any future changes can be compared, it is suggested that this should always be considered in the context of the relative benefits and disadvantages of proactive screening (BPS DCP & RCP, 2015).

Declaration of Conflicting Interests: The Authors declare that there is no conflict of interest.

Funding: This work was supported by NHS Lothian

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